Dementia NI
Principles of Engagement
Best Practice Guidelines

Dementia NI ask that those seeking our views come with the attitude that they, and the organisation which they represent, desire to make a positive and lasting change in our lives, and in the lives of others in Northern Ireland who live with dementia now and in the future.

We ask that you follow these principles to ensure a positive experience for both Dementia NI members and those who wish to involve members in a project or research.

Due to the sensitive and confidential nature of our work, Dementia NI must ensure a Duty of Care to our members, volunteers, and staff. Dementia NI must be made aware of the names of each individual, job title and organisation liaising with Dementia NI and their purpose in attending prior to the event, workshop, or meeting.

Everyone must complete and return a Dementia NI Request Form prior to collaboration with Dementia NI stating their purpose and intention for the interaction and how it fits with the strategic direction of our organisation.

Our Vision

Everyone living well with dementia

Our Mission

People with dementia driving positive change

Aims

- Challenge the stigma of having a diagnosis by raising awareness about dementia
- Promote the right for people living with dementia to be involved in decisions that affect their lives
- Provide training, education and awareness to organisations and the public on how to best support people living with dementia
- Support people living with dementia to raise awareness of dementia in their own right.

Values

- Led by people with dementia
- Inclusive and accessible
- Striving for meaningful change
- Being heard and understood

A company limited by guarantee NI628713. Registered with the Charity Commission for Northern Ireland NIC106148.

- Dementia NI is committed to meaningful engagement and through experience is aware of a risk that visitors may attempt to engage Dementia NI members, often unintentionally or unknowingly, as a tick box exercise when working alongside people with dementia; therefore, we require all individuals/organisations working with us to sign a 'Closing the Loop' disclaimer on the Dementia NI Request Form.

- Dementia NI has a Duty of Care to protect our members from being bombarded by third party contacts that are made through our organisation. Therefore, outside parties who work with members through Dementia NI projects agree to refrain from contacting members privately. This could be (but not limited to) by telephone, post, email, in person or by social media. Any contact with members must be made through Dementia NI. Individuals and organisations **MUST NOT** ask Dementia NI members for personal contact details at any time.

- Making your engagement more accessible will make life a lot easier for our members living with dementia. Dementia NI is part of the Dementia Engagement and Empowerment Project (DEEP) network. DEEP groups have produced many resources that will help your engagement run more smoothly and effectively. We kindly ask you to consider following this good practice before your engagement. Resources can be found at: https://www.dementiavoices.org.uk/deep-resources/

Coming to an Empowerment Group Meeting

How you can prepare.

- Ensure that Dementia NI group members have been fully informed about the purpose of the activity or project that they are requested to participate in.

- Dementia NI members request that visitors attend with visual aids which may be used to reinforce information. Visual aids include the use of your agenda and the desired outcome from our views, leaflets, photographs, images, and videos. This assistance will further aid group members and facilitate better understanding of what the activity or project would be.

- Please consider Dementia NI members' priorities. What you may deem as vitally important may not necessarily be deemed as helping the lives of Dementia NI members and others living with dementia. All interactions are an opportunity to share experience and learning with the intention of achieving the best outcomes for people with dementia.

- Dementia NI members require honesty and transparency. We request that you do not refrain from informing us of anything you feel that we may not like.

Keep It Simple.

- Speak in simple language using layman's terms. People with dementia come from all sorts of backgrounds and educational status, please develop your activity/project to accommodate everyone.

- Explain things in a variety of ways. We may not understand one method of explanation, but do not let that put you off. Please try again, using different wording and simpler terminology or from a different angle. Together we will get there.

A company limited by guarantee NI628713. Registered with the Charity Commission for Northern Ireland NIC106148.

- All documents presented to us must be displayed in a clear concise way.

    - Please do not use acronyms or abbreviate terms.
    - Summarise when possible.
    - Explain terminology and refrain from using jargon.
    - Develop Terms of Reference.
    - Use appropriate language which will not offend a person with dementia.

- Keep all wording in simple understandable language.

- On occasions Dementia NI members can feel overwhelmed by too much information or reading, therefore request that visitors do not bring bundles of papers which require a lot of reading and concentration. Please refer to the DEEP guides on making things more accessible. These can be found at: https://www.dementiavoices.org.uk/deep-resources/making-things-more-accessible/

Using quotes, images, and recordings.

- Dementia NI members request that visitors use our opinions and life experiences as knowledge. Please take this knowledge into account for further development of future projects or activities.

Quotations

- Dementia NI meetings will be recorded for group members to later clarify information discussed within consultations if required. Dementia NI record Empower and Support Group meetings by Dictaphone/Zoom for future reference. These recordings are kept confidential and secure in line with GDPR. On occasions this information may be used for publicity or on social media, but only with the consent of all involved. Dementia NI request that consent forms be issued by outside organisations/individuals should they wish to gain quotations from a Dementia NI member or in a Empower and Support meeting. Dementia NI request a copy of all consent forms collected.

  Should individuals or organisations use quotations or comments made by Dementia NI members, we request that you contact Dementia NI staff who will check and clarify the quote is correct and that the members still consent to have the information printed. Any comments regarding Dementia NI should be checked to be factually correct before publishing documents.

Photographs and Filming

Dementia NI may take photographs of the group during the activity/project for marketing and social media purposes. By participating, you and your organisation give consent for Dementia NI to use any photos/filming and recognise your organisation's contribution.

- Please be aware that consent must be gained for images of Dementia NI members in photos and recordings. Dementia NI must agree to the content of consent forms for each activity/project involving outside organisations and how the images will be used. Dementia NI must be informed where the images will be used and be given a copy of a blank consent form for administration records.

- Dementia NI will protect your details under GDPR, and we expect all individuals and organisations to do the same with members' details, including their full name, locality and any images taken. No details or images must be shared with third parties without prior written consent.

Coproduction, Personal and Public Involvement (PPI), Consultation and Steering Groups.

Please keep us safe.

- Dementia NI members may on occasions discuss personal experiences. Any information shared must be treated in a strictly confidential manner and not discussed or used as a case study without written consent. This includes but is not limited to the change of name or details of the experience. **Should a safeguarding issue arise or if a Dementia NI member discloses information deemed a concern regarding the safety of themselves or another individual, it is your duty to make Dementia NI staff aware IMMEDIATELY in order to deal with the issue appropriately.**

- Ensure the environment where we meet is both physically and emotionally safe. If you require advice, please feel free to ask Dementia NI Empowerment Officers for hints and tips.

- Consider our experience - do not ask us to go back to unhappy times or relive unpleasant experiences. By doing so, you may make us relive bad memories, or emotions relating to painful times.

- Be aware that activities involving outside individuals/organisations have the potential to take people living with dementia outside of their secure environment. We ask you to be prepared and ready to respond.

A company limited by guarantee NI628713. Registered with the Charity Commission for Northern Ireland NIC106148.

- It is good practice to ensure that group members remain happy to continue in participation of any activity/project. Consent should be continually re-sought, please ask regularly if members are happy to continue.

- Offer Dementia NI members reassurance and ask us if we need to take a break. Regular rest breaks should always be made available throughout the activity/project.

- People living with dementia tend to lose concentration when the activity is prolonged, therefore projects/activities must be within a reasonable time frame suitable to the ability of our Dementia NI members. This can be agreed in advance with participating group members.

- If a Dementia NI member has withdrawn consent, does not confirm consent, is incapable of giving consent or has changed their mind then the exercise must be ended.

- Please keep yourself safe and remain within your own physical and emotional boundaries.

Keep us informed.

- Dementia NI requires a follow up email which sums up your understanding of the requests and opinions of Dementia NI members to ascertain that relevant information and opinions have been properly understood by all parties concerned.

- For our views to make a full impact we request that Dementia NI members' involvement is acknowledged when the activity/project is referenced in publications, through the media, and through all other outlets.

- Dementia NI require acknowledgement of our organisation's involvement in all activities and projects. The contribution of Dementia NI should be recognised in publications and media, applying the Dementia NI logo when appropriate. Please inform Dementia NI when our logo will be used within publications and refer to Dementia NI Brand Guidelines. Brand Guidelines are available on request by emailing communications@dementiani.org

- Dementia NI members wish to help influence policy, practice, service delivery and support to meet local needs. We want our views to be valued. Therefore, we require to be kept informed as to how our members' views have influenced policy, direction, or service. We require all visitors to feedback to Dementia NI; to explain how group members' views have influenced policy, direction, or service and to ensure that Dementia NI group members views are being appropriately taken on board and utilised. Dementia NI welcomes visitors to come back to inform members of the outcomes of any activities or projects that we have been involved in.

- Dementia NI require feedback as to how our involvement in a project or research has been utilised for the better of people living with dementia and to confirm that Dementia NI member's views are being appropriately taken on board and employed. This feedback will be time bound in line with the agreed length of the project. Individuals and organisations collaborating with Dementia NI must agree to a timeframe and state this information on the Request Form when they intend to inform us of outcomes.